Spiritual and Religious Coping of Medical Decision Makers for Hospitalized Older Adult Patients

Saneta M. Maiko,[1-3] Steven Ivy,[4] Beth Newton Watson,[5] Kianna Montz,[1] and Alexia M. Torke[2,3,6]

Abstract

Background: Critically ill adult patients who face medical decisions often delegate others to make important decisions. Those who are authorized to make such decisions are typically family members, friends, or legally authorized representatives, often referred to as surrogates. Making medical decisions on behalf of others produces emotional distress. Spirituality and/or religion provide significant assistance to cope with this distress. We designed this study to assess the role of surrogates' spirituality and religion (S/R) coping resources during and after making medical decisions on behalf of critically ill patients. The study's aim was to understand the role that S/R resources play in coping with the lived experiences and challenges of being a surrogate.

Methods: Semistructured interviews were conducted with 46 surrogates by trained interviewers. These were audio-recorded and transcribed by research staff. Three investigators conducted a thematic analysis of the transcribed interviews. The codes from inter-rater findings were analyzed, and comparisons were made to ensure consistency.

Results: The majority (67%) of surrogates endorsed belief in God and a personal practice of religion. Five themes emerged in this study. Personal prayer was demonstrated as the most

This is the author's manuscript of the work published in final form as:

Maiko, S. M., Ivy, S., Watson, B. N., Montz, K., & Torke, A. M. (2018). Spiritual and Religious Coping of Medical Decision Makers for Hospitalized Older Adult Patients. *Journal of Palliative Medicine*, *22*(4), 385–392. https://doi.org/10.1089/jpm.2018.0406

important coping resource among surrogates who were religious. Trusting in God to be in charge or to provide guidance was also commonly expressed. Supportive relationships from family, friends, and coworkers emerged as a coping resource for all surrogates. Religious and nonreligious surrogates endorsed coping strategies such as painting, coloring, silent reflection, music, recreation, and reading. Some surrogates also shared personal experiences that were transformative as they cared for their ill patients.

Conclusion: We conclude that surrogates use several S/R and other resources to cope with stress when making decisions for critically ill adult patients. The coping resources identified in this study may guide professional chaplains and other care providers to design a patient-based and outcome-oriented intervention to reduce surrogate stress, improve communication, increase patient and surrogate satisfaction, and increase surrogate integration in patient care. We recommend ensuring that surrogates have S/R resources actively engaged in making medical decisions. Chaplains should be involved before, during, and after medical decision making to assess and address surrogate stress. An interventional research-design project to assess the effect of spiritual care on surrogate coping before, during, and after medical decision making is also recommended.

Keywords:

coping; medical decision making; religion; spiritual care; spirituality; surrogate

Author Affiliations:

[1] Indiana University Health, Indianapolis, Indiana.

[2] Daniel F. Evans Center for Spiritual and Religious Values in Healthcare, Indianapolis, Indiana.

[3] Center for Aging Research, Regenstrief Institute, Inc., Indiana University, Indianapolis, Indiana.

[4] Association of Clinical Pastoral Education (ACPE), Decatur, Georgia.

[5] Spiritual Care and Chaplaincy Services, Indiana University Health, Indianapolis, Indiana.

[6] Division of General Medicine and Geriatrics, Indiana University, Indianapolis, Indiana.

Introduction

Since critically ill patients often need others to communicate and make decisions for them, doctors frequently ask others such as close friends or family members to serve as patients' surrogate decision-makers. Research shows that between 24% and 47% of medical decisions for patients hospitalized for life-threatening illnesses are made by surrogates.[1–6] Studies show that surrogates experience high levels of distress[7–9] because of the severe illness of a loved one, anticipatory grief, and poor clinician-family communication.[10–13] How, then, do surrogates of critically ill patients deal with the stressors they experience? When faced with major life crises, many people use spirituality and religion (S/R) as coping strategies.[14–17] Spirituality and/or religion promote healthy adaptation to significant life events.[18] It is therefore possible that S/R resources are important coping strategies for surrogate decision-makers.

According to Monod et al., spirituality "often include[s] a sense of transcendence beyond one's immediate circumstances and other dimensions such as purpose and meaning in life, reliance on inner resources, and a sense of within-person integration or connectedness."[19] Puchalski and Romer defines spirituality as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."[20] These relationships around the person reflect a "holistic dimension" that is often guided by family-system perspectives.[21]

Our approach uses the aforementioned broad concept of spirituality and explicitly includes its relational aspects. Religion is defined more narrowly as something that is "often community focused, organized, observable, measurable, objective, behavioral, and sometimes doctrinal oriented."[22] Gallup reports that 90% of adults in the United States express a belief in God or a

Higher Power, and 70% of adults see religion as an important component that influences their lives.[23] We explored both religion and spirituality in our investigation.

Previous studies have found that S/R resources play significant roles in coping among caregivers in outpatient settings.[24,25] A study among caregivers of mental-health patients found that caregivers frequently engage in private prayer and seek spiritual guidance in making decisions in their everyday life.[26] A study of 1229 caregivers of dementia patients found religion to be a significant factor in coping. The study also found that ~77% of the respondents prayed nearly every day, and 70% perceived their faith to be of great value.[26,27] Studies of patient spirituality also found that positive religious coping for patients significantly contributes to the reduction of S/R distress among family members.[28–32]

The coping process may be somewhat different when the caregiver is called upon to make decisions and when the patient is acutely ill and in the hospital. Some prior studies have identified Spirituality and/or religion as one of several factors in surrogate coping. One published framework identified the following four factors that are essential to surrogates in honoring patients' care preferences: (1) the emotional impact of the decision-making process on the surrogate; (2) the difficulty of watching a loved one's health deteriorate; (3) the importance of having a Living Will or other written or spoken instructions; and (4) the reliance on spirituality as a means of coping with the surrogate experience.[33] Another study examined what helps or hampers the experience of making medical decisions for others and found four important factors as follows: (1) the surrogates' social networks, including faith communities; (2) surrogate–clinician communication and their relationship; (3) the surrogate–patient relationship; and (4) the surrogates' characteristics and life circumstances.[34] However, there is little empirical research describing in greater depth the role of spirituality and/or religion in surrogate coping. The goal of

this study was to gain a deeper understanding of the S/R coping resources used by surrogates of hospitalized older adults. Further studies that explore S/R coping more extensively could guide spiritual-care providers for the family members of seriously ill patients.

Methods

Research design

We conducted a qualitative analysis of audio-recorded semistructured interviews with surrogate decision-makers to examine the use of S/R in coping with the surrogate experience. This study was a secondary analysis of qualitative data collected for a larger prospective study of surrogates' decision making.[35] This study was approved by the Institutional Review Board at Indiana University.

Participants and recruitment

We enrolled patient/surrogate dyads in the study. The participants were recruited from an urban public hospital in the United States' Midwest and from a university-affiliated tertiary referral center. To identify eligible patients, electronic medical records for every newly admitted adult aged 65 years and older were reviewed by research-team members, and a brief interview was conducted with each potential participant's treating physician.

Study eligibility for patients was defined as hospitalization of at least 24 hours, with a determination by the patient's treating physician that a major medical decision (related to life-sustaining treatments or code status, procedures, and surgeries or placement in another facility at discharge) was likely during the current admission and that the presence of a surrogate decision-maker was also needed, owing to the incapacitated status of the patient. The legally authorized

surrogates were identified either by the patient before illness or as authorized based on state law. Surrogates were ineligible if they could not participate in an interview in English.

Data collection

Interviews with surrogate decision-makers of hospitalized older adults were conducted by an investigator or by a research assistant trained in qualitative research interviews. The interviewers carried out the interviews using a semistructured interview guide. Interviews were conducted in either a private location in the hospital or the surrogate's home. Each interview was audio-recorded and transcribed verbatim.

Consistent with standard qualitative research methods,[32,36] we used an iterative process for the original data collection that went back and forth between data collection and data analysis and included the modification of our research interviews and our recruitment strategy as information about surrogates' S/R was obtained.[35,37]

The interview guide used for the first 35 participants included only a few questions about spirituality and/or religion. Because we knew from our prior research and experience that S/R resources are often important to surrogates, we revised our interview to ask additional questions about these topics. Two questions and several probing questions directly addressed S/R experiences: “How did your religious or spiritual beliefs play a role in your experience when [patient] was in the hospital,” and “What religious or spiritual practices helped you in these times?” However, since some surrogates mentioned S/R concerns at other points in the interview, we included all responses related to S/R in this analysis.

We used purposeful sampling to ensure adequate numbers of participants in which life-sustaining treatment decisions were considered, given the importance of S/R in these decisions. We reached

theme saturation after a total of 46 interviews. The interviews took place from June 2011 through January 2012. Seventy-six percent of the participants were female, 50% were white, 50% were African American, and 57% daughters. Religion was discussed in 60% of the first 35 interviews and in all subsequent interviews.[37]

Data analysis

For the current secondary analysis, three independent investigators (S.M., A.M.T., and S.I.) analyzed data using thematic analysis. We followed two levels of coding to ensure credibility within our study. We started with open coding by reading through audio-recorded transcribed data; then we created tentative labels for portions of data that summarized what we saw happening (based not on existing theory but on the meaning that emerged from the data). We recorded examples of participants' words and established the properties of each code. Based on principles of grounded theory as developed by Glaser and Corbin (1967),[52] we then identified relationships among the open codes and developed draft themes. Finally, we entered into selective coding by reviewing all transcripts and applying the final set of codes. We calculated inter-rater agreement in the use of codes when core themes and subthemes emerged with 82% inter-rater agreement.

Results

We conducted a total of 46 interviews out of 119 eligible surrogates. Seventy-six percent of the surrogates were female, 50% were white, and 50% African American. Forty-eight percent of our participants identified as Protestant-Christian. Mostly daughters (57%) were the ones who made decisions in consultation with their patients. Reviewers achieved an inter-rater agreement of 82%.

This study yielded five major themes as follows: personal prayer, trusting in God, supportive relationships, transforming experiences, and spiritual activities such as art and recreation. A number of surrogates in this study identified with a Christian religion and used religious language such as “God” and “prayer” to describe their spiritual activity. We will now discuss these coping resources as described to us by surrogates.

Personal prayer

The majority of religious participants stated that personal prayer was a source of hope and comfort. For some, this was also an important practice in their life before the patient's illness, as explained by one participant.

Well, we pray every day, so it. .. didn't change. It's just something that we do. (002a)

Personal prayer was regarded as the central and most important spiritual activity for many. As one surrogate said:

All I can do is pray. .. and I do believe in prayer, and God does answer sincere prayer. (005)

Personal prayers, especially when perceived as answered, were described as giving strength to the surrogate. A participant explained how prayer helped this way and in overcoming fatigue:

[M]y prayers basically got answered. My mom's prayers got answered when mine did because she would always, she would never talk about death with me.. .. So, you know, prayer has kept me going because I am tired. (004a)

Another participant voiced the role prayer plays in getting him through difficult life events:

I pray all the time and God pulls me through these really bad things that I feel in my life, but there are other things that are worse. I have. .. I turn a negative into a positive.. .. And so I have

to deal with all that on the sideline. So. .. I trust this care more and to get this done and get it where we can move on and however long God has her here. (009)

Prayers from others such as the person's faith communities and friends were also valued as sources of support. Some surrogates requested prayers from others.

B——and I both prayed with J——at times. And to be honest with you, I had recruited a lot of other people to be praying for her as well. (0019)

One surrogate described her experience of others' prayers this way:

Every day she calls me or texts me saying, “How's mom doing, how's she doing, is she going to be all right, you know I'm praying for you.” It's just. .. just positive energy, you know, from somebody that really knows her, you know.

Prayers from friends were also highly valued.

I have a group of friends that, you know, I've communicated with and they've all sent up their prayers and they've been calling me and, you know, so. .. And we've been updating back and forth. (0034)

Other religious practices, although less important than prayer, were also identified as important coping resources. These practices included reading scripture silently or to the patient.

My sister reads to him at night.. .. When she comes in, she will read different scriptures to him. (008a)

Trust in God

Several surrogates expressed trust in God that included both acknowledging God's power over events and a sense of being guided by God. This trust allowed the surrogate to let go of worry or a sense of responsibility for the outcome of the illness.

You know, she's 86 but she got a sharp mind and she tell[s] me the same thing, you know, put it in God's hands. You know, God will do this and God will do that, you know. There isn't anything you can do about it. (007a)

In this case, the surrogate was comforted by her own faith and the knowledge of the patient's faith. Another surrogate felt that God was guiding her decision-making.

I think God showed me that my decision was right. That same day when I was crying and really kept praying was this right decision, two priests came to visit me, and two separate different priests came. They said they understood my position, and I wasn't wrong. So I know God loves me, so just leave it at that. (007b)

The aforementioned participant also demonstrates the importance of clergy visits during the hospitalization.

Knowing that a loved one is spiritually at peace may relieve a surrogate from worry and distresses.

She's, yeah, she's pretty, she's pretty, um, safe, you know, with it, spiritually. Yeah. She'll say, “You know, it doesn't matter because I'm old.” You know? She just said, “If. .. if it's my time to go, it's my time to go. If God calls me. .. is calling me, then I don't want them to interrupt it or whatever like that.” (006b)

Trusting God may be based on different interpretations of sacred text.

Even Christians feel about, you know, when you die, what do you take, what's in the Bible literally or figuratively.. .. Before you're born, He says, you know, He's already counted your days. (0013)

One participant described how he prayed for strength and believed God would not give him a burden he couldn't bear.

Well, let's see. Uh, mm, I don't know. God, I guess prayer [because], you know, I believe what the Bible says. He won't put no more on me than you can bear and so, you know, I just say, “Okay, I need the strength. Give me strength. I need more strength.” You know? Like that and that's what I do.. .. So, that's how I get through it. Um, other than that, I would collapse. (001)

Another participant had this to share:

Umm. .. sometime[s] I just say, “You know, Lord have mercy,” you know, mercy plead a better case. Like I say, nothing you can do about it, so, you know, saying “God, [I'm] ready.” You just got to leave it alone and let him do what he does. (008)

Supportive relationships

We learned that relationships from hospital staff, friends, a faith community, and even other patients' families were important sources of support.

Staff

Hospital staff (e.g., doctors, nurses, chaplains, therapists, and social workers) provided substantial support that led to a sense of trust and reassurance. One participant explained:

Well, one guy I knew was a neurologist. I knew he would be the expert knowing what was wrong with her and the same with the kidney doctor that came in the same way; and, they were

both very, very informative, very personable, took the time to explain, you know, try to explain things so we'd understand it and I think they did a good job. (004b)

Excellent communication from staff may be a source of peace, as one participant confirmed:

Just excellent communication. The doctors called me back when I had questions, and I had notes left on the chart. They just always explained everything. The [staff member] that did the physical therapy was just a peach and always very much a teacher. The. .. Dr. H——was kind of a teacher. (003)

Chaplains

Although we did not find evidence that the medical team explicitly discussed religion or spirituality, their expertise contributed to surrogates' coping with caring for the patient. This was because they understood the details about what the patient was going through. Chaplains, however, were explicitly identified as sources of spiritual and emotional support. As one surrogate reported:

[T]he one thing that is good is that you do have chaplains, and chaplains came by and prayed with her at times. (0019)

Chaplains also provided rituals such as the sacrament of the sick, which lessened surrogate distress.

One of them was the priest that had done my mom's sacrament of the sick, and he said he understood exactly what I was saying and that until she reached that point where, you know, it would ease her pain and help her make the transition easier, more. .. less difficult,. .. then, you know, that it was a good decision. (007c)

Some expressed a desire to have a chaplain visit, while others did not even know the role of a chaplain. When asked whether she requested a chaplain, one participant described the role of the chaplains as something other than supportive.

A lot of comfort, well, and sometimes it scares them. You know? About to see, when you see a priest or a chaplain heading toward you. It's not going to be good news.. .. And that, that's one thing that they have a problem overcoming because people would just kind of associate a chaplain with something that's not going to be good news. (005)

One surrogate shared limited knowledge about the role of a chaplain, showing that she did not know she could even ask for a chaplain.

No, there wasn't anything. Now, I don't know. I don't remember if there's anything about calling a chaplain or not. There might've been something about that but, you know, she probably didn't need a chaplain. She needed somebody to say, “You know, here's why you're living. You know, you got to get up and do it. Maybe that's the chaplain, you know. (0025)

Family and friends

Some surrogates discussed how their network of social support played a role in their ability to cope.

Support from my family, his sister with my mom, talking to her and his younger brother, and just kind of being in agreement with things and then supporting what we're doing and knowing that we're all kind of in this together and all agreeing. Nobody's going against each other or butting heads about. .. what's going to be done and how things are going to be taken care of. (006c)

Faith community

A number of participants described how clergy and faith community played a significant role in helping them cope. We found that visits from clergy and congregants, together with their prayers, had an impact on surrogates. One surrogate convincingly described the effect:

I would turn to my pastor or a member of the church, you know, like a person older than you that's more experienced and been there and done that. .. I would turn to them and sometime[s] they can give you good advice, whether you take it or not, you know. (0016)

Prayer and connection with one's own faith community may also be a good coping resource for other surrogates.

So, I mean, we had that connection. Oh, well, you always are glad to see, you know, another brother or sister in Christ. That, uh, that's a very comforting thing. (006d)

We also heard from another surrogate, who explained a similar effect:

I think.. ., once I had the talk with. .. one of my pastors.. .. That, plus we had all my Banquet brothers and sisters. .. [who] were all praying and supporting. You know? So, you know, we had a. .. a big support group. (0010)

Spiritual practices

When asked how they coped using S/R, some surrogates made the distinction of relying on spiritual sources of support—such as turning to nature—to cope. These approaches were especially important for surrogates who did not identify as religious.

I also do watercolor and oil.. .. When you're doing that, you don't think about other things. You just kind of clear your mind and feel. (008)

Solitude was also cited as a coping mechanism.

Just trying to relax and take a few minutes for myself every now and then, just to keep it together. You know, just.. .. I wouldn't really say meditation. Just getting somewhere quiet and just spending a little down-time all to myself and nobody else around. (008b)

Another participant expressed coping this way:

Oh, yeah,. .. you know, be a person, be out there in the world, listen to music, watch art, look at television. (0018)

Transforming personal experiences

In the above quotations, patients often revealed negative emotions such as stress, anxiety, or fatigue. We found that when surrogates described their coping, they also described positive changes, which we call transformation. This transformation often led to a sense of peace, acceptance, and/or reassurance. One Catholic surrogate described how talking with a spiritual leader and others influenced her and brought her reassurance and calm.

Well, after having talked with that pastor and cried all over him, and then talking with Dr. “G” and crying all over him about my viewpoint and how unhappy my brother was with me about my decision, and I'd asked to talk with the priest.. .. And I explained the reasons why I wanted to talk to him, and he was very, very good, very reassuring about what the church's position was, and. .. you know, supportive of my position. (0010)

Another participant said more about acceptance as a decision to cope this way:

No, I've accepted it. .. because. .. I've been following his case. .. and I know that he has prostate cancer. .. on top of all the other things that's going on with him. .. and whether some of them have. .. intertwined and there are. .. different symptoms that cause or are affected by the cancer.

Some of them are. .. other things that are happening to him. .. so. .. I've accepted that fact. .. that he could pass. (002b)

This quotation clearly demonstrates how surrogates interpret the circumstances they face, especially when they have difficulties with risky prognoses. Acceptance remains a key coping strategy for some participants, which indicates the stable transformation within a surrogate.

Discussion

Interviews with surrogates for seriously ill hospitalized adult patients revealed several specific ways in which S/R resources promote coping. For religious surrogates, two important themes emerged: prayer and trust in God, both of which fundamentally relate to the surrogate's relationship with God. Some surrogates, including those who do not identify as religious, described solitary activities such as creating or enjoying art and being in nature as important resources for coping. In addition, close relationships are also clearly important to both religious and nonreligious surrogates. Such S/R experiences may lead to a transformational experience in which surrogates cope with negative emotions such as distress, fatigue, or worry.

The S/R themes we identified have been identified as a part of coping in other research. A study by Weaver and Flannelly concludes that "[t]he feeling that one has a positive relationship with God can give an individual a sense of self-acceptance and belonging and also provide a source of emotional comfort when faced with a life-threatening illness."[38] Pargament et al.[39] also establishes the possibility that prayer may help during distressing times. This research shows that prayer positively helps during distressful moments. Although Pargament et al.'s research also detailed how some prayers may become a negative coping strategy, our findings did not reveal negative religious coping.

The use of prayer to help distressed surrogates cope has been discussed by Krause and Hayward[40] in detail. In Krause and Hayward's research, prayers and especially trust-based prayer beliefs offer a certain kind of life comfort and satisfaction. Furthermore, surrogate experiences of support from faith leaders are in agreement with prior studies[41–43] that confirm support from spiritual leaders and their communities to be significant for coping among patient caregivers. Other research also supports the fact that "trusting God" by letting God take full control of everything is a coping resource.[38]

Given our observation that many surrogates rely on S/R coping mechanisms and value support from chaplains and clergy, additional S/R support may reduce the high degree of distress that surrogates face when their loved ones are critically ill and hospitalized. Researchers such as Puchalski and Romer[20] have challenged physicians to encourage people with end-of-life concerns to express S/R concerns as a means of coping. Referral to S/R resources could reduce surrogates' concerns, especially when those concerns are understood by attending doctors who are fully aware of patients' spiritual distress.[44,45] However, research has also shown that physicians are unskilled and have limited time to provide spiritual care to patients who are approaching the end of life.[43] Interdisciplinary team members such as chaplains, nurses, and social workers should be carefully engaged and integrated in reinforcing and/or clarifying that diagnostic and prognostic information while caring for surrogates.[46,47]

In the present study, only a few surrogates of incapacitated hospitalized patients received care from hospital chaplains, who have the professional skills to do this work. Some surrogates did not understand the work of chaplains in the hospital. Spiritual care providers may bolster the spiritual strengths of family members through listening and clarifying concerns while forming meaningful relationships with patients and family members. However, sometimes surrogates

miss spiritual support from chaplains because of the chaplains' lack of availability and competing demands.

Addressing the aforementioned concerns will require a careful and strategic integration of spiritual care in hospitals. All members of care teams could participate in basic spiritual history taking. Several methods have been proposed to train nonchaplains in this endeavor.[48–50] Addressing family concerns would be consistent with recommendations from the American College of Critical Care Medicine Task Force 2004–2005, one of which is the inclusion of spiritual care in patient-centered intensive-care units.[50] Just as spiritual resources have been found to contribute to coping among newly diagnosed gynecological cancer patients,[51] we found that surrogates see S/R resources as meaningful in coping with the stress of medical decisions they make.

Our study has a number of strengths. First, we conducted a semistructured interview and blinded the inter-rater readers to the outcomes. Qualitative inquiry invites a person's life story to be more fully expressed and allows researchers to propose a clinical practice strategy based on the participants' own experiences. Second, this study offers findings that may influence clinical practice adjustment, spiritual-care intervention design, and effective team building, and possibly communication in critical care situations.

This study has several limitations. Any study that does not attend to causality shows limitations in its design. Additional limitations include our use of cross-sectional design and the selection of study participants from just one metropolitan area and two hospitals in that area. We cannot assume that the same results would apply in other populations. Our population was highly religious and specifically Christian, which may yield very different results in studies involving other health care institutions and cities. We also focused our study on spiritual and religious

coping, and our participants did not share information with us about any alternative coping strategies such as substance abuse and drug use. For these reasons, it is difficult to generalize the findings of our study without caution.

The finding that S/R resources are important for bolstering better coping suggests opportunities to increase the well-being of family surrogates through spiritual care from both chaplains and interdisciplinary teams. To better provide S/R support, chaplains should be accessible and active in meetings between interdisciplinary teams and families which aligns with Geros-Willfond et al.'s[37] study. Our study suggests that for surrogates who claim spirituality and/or religion, prayer and trust in God are especially important. Since not all coping strategies that were mentioned were religious or spiritual, we encourage caregivers to be aware of the significance of close relationships, personal strength, and other coping resources from surrogates and to attend to them. Finally, further outcome-oriented research is needed to assess the effect of spiritual care on surrogate decision-makers' spiritual and emotional health outcomes.

Acknowledgments

This article would not have been brought into fruition without the support from all those involved through review readings. The research received funding from NIA Grant K23ag031323, The John A. Hartford Foundation, and the American Geriatric Society and the Daniel F. Evans Center for Spiritual and Religious Values in Health care at Indiana University Health. These funders had no role in designing the methodology, recruitment of participants, data collection and analysis, or article writing.

Author Disclosure Statement

No competing financial interests exist.

References

1. Torke AM, Alexander GC, Lantos J, Siegler M: The physician–surrogate relationship. Arch Intern Med 2007;167:1117–1121.

2. Torke AM, Sachs GA, Helft PR, et al.: Scope and outcomes of surrogate decision making among hospitalized older adults. JAMA Intern Med 2014;174:370–377.

3. LeClaire MM, Oakes JM, Weinert CR: Communication of prognostic information for critically ill patients. Chest 2005;128:1728–1735.

4. Kim SY, Karlawish JH, Caine ED: Current state of research on decision-making competence of cognitively impaired elderly persons. Am J Geriatr Psychiatry 2002;10:151–165.

5. Raymont V, Bingley W, Buchanan A, et al.: Prevalence of mental incapacity in medical inpatients and associated risk factors: Cross-sectional study. Lancet 2004;364:1421–1427.

6. Prendergast TJ, Claessens MT, Luce JM: A national survey of end-of-life care for critically ill patients. Am J Respir Crit Care Med 1998;158:1163–1167.

7. Wendler D, Rid A: Systematic review: The effect on surrogates of making treatment decisions for others. Ann Intern Med 2011;154:336–346.

8. Christakis NA, Iwashyna TJ: The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. Soc Sci Med 2003;57:465–475.

9. Siegel K, Raveis VH, Mor V, Houts P: The relationship of spousal caregiver burden to patient disease and treatment-related conditions. Ann Oncol 1991;2:511–516.

10. White DB, Engelberg RA, Wenrich MD, et al.: Prognostication during physician-family discussions about limiting life support in intensive care units. Crit Care Med 2007;35:442–448.

11. Rabow MW, Hauser JM, Adams J: Supporting family caregivers at the end of life: “They don't know what they don't know.” JAMA 2004;291:483–491.

12. Hauser JM, Chang CH, Alpert H, et al.: Who's caring for whom? Differing perspectives between seriously ill patients and their family caregivers. Am J Hosp Palliat Care 2006;23:105–112.

13. Azoulay E, Chevret S, Leleu G, et al.: Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med 2000;28:3044–3049.

14. Bussing A, Janko A, Baumann K, et al.: Spiritual needs among patients with chronic pain diseases and cancer living in a secular society. Pain Med 2013;14:1362–1373.

15. Murray SA, Kendall M, Boyd K, et al.: Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their carers. Palliat Med 2004;18:39–45.

16. Grant E, Murray SA, Kendall M, et al.: Spiritual issues and needs: Perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. Palliat Support Care 2004;2:371–378.

17. Puchalski C, Ferrell B, Virani R, et al.: Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. J Palliat Med 2009;12:885–904.

18. Gall TL, Charbonneau C, Clarke NH, et al.: Understanding the nature and role of spirituality in relation to coping and health: A conceptual framework. Can Psychol 2005;46:88.

19. Monod S, Brennan M, Rochat E, et al.: Instruments measuring spirituality in clinical research: A systematic review. J Gen Intern Med 2011;26:1345–1357.

20. Puchalski C, Romer AL: Taking a spiritual history allows clinicians to understand patients more fully. J Palliat Med 2000;3:129–137.

21. Fitchett G: Assessing Spiritual Needs: A Guide for Caregivers, Rev. ed. Lima, OH: Academic Renewal Press, 2002.

22. Koenig HG, McCullough ME, Larson DB: Handbook of Religion and Health. Oxford, United Kingdom: Oxford University Press, 2001.

23. Pew Research Center. Religion and public life Religious research study, 2014. http://www.pewforum.org/religious-landscape.study/belief-in-god (last accessed October 2, 2018).

24. Pargament KI, Ano GG, Wachholtz A: The religious dimension of coping. In: Paloutzian RF, Park CL (eds): Handbook of the Psychology of Religion and Spirituality. New York: Guildford Press, 2005, pp. 479–495.

25. Taylor EJ, Outlaw FH, Bernardo TR, Roy A: Spiritual conflicts associated with praying about cancer. Psychooncology 1999;8:386–394.

26. Hebert RS, Dang Q, Schulz R: Religious beliefs and practices are associated with better mental health in family caregivers of patients with dementia: Findings from the REACH study. Am J Geriatr Psychiatry 2007;15:292–300.

27. Aslakson RA, Kweku J, Kinnison M, et al.: Operationalizing the measuring what matters spirituality quality metric in a population of hospitalized, critically ill patients and their family members. J Pain Symptom Manage 2017;53:650–655.

28. Kaye J, Robinson KM: Spirituality among caregivers. Image J Nurs Sch 1994;26:218–221.

29. Zwingmann C, Wirtz M, Muller C, et al.: Positive and negative religious coping in German breast cancer patients. J Behav Med 2006;29:533–547.

30. Balboni TA, Vanderwerker LC, Block SD, et al.: Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. J Clin Oncol 2007;25:555–560.

31. Sherman AC, Simonton S, Latif U, et al.: Religious struggle and religious comfort in response to illness: Health outcomes among stem cell transplant patients. J Behav Med 2005;28:359–367.

32. Giacomini MK, Cook DJ: Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. JAMA 2000;284:357–362.

33. Buckey JW, Molina O: Honoring patient care preferences: Surrogates speak. Omega 2012;65:257–280.

34. Vig EK, Starks H, Taylor JS, et al.: Surviving surrogate decision-making: What helps and hampers the experience of making medical decisions for others. J Gen Intern Med 2007;22:1274–1279.

35. Torke AM, Petronio S, Purnell CE, et al.: Communicating with clinicians: The experiences of surrogate decision-makers for hospitalized older adults. J Am Geriatr Soc 2012;60:1401–1407.

36. Lindlof TR, Taylor BC: Qualitative Communication Research Methods, 3rd ed. Los Angeles, CA: Sage, 2010.

37. Geros-Willfond KN, Ivy SS, Montz K, et al.: Religion and spirituality in surrogate decision making for hospitalized older adults. J Relig Health 2016;55:765–777.

38. Weaver AJ, Flannelly KJ: The role of religion/spirituality for cancer patients and their caregivers. South Med J 2004;97:1210–1214.

39. Pargament KI, Ensing DS, Falgout K, et al.: God help me: Religious coping efforts as predictors of the outcomes to significant negative life events. Am J Community Psychol 1990;18:793–824.

40. Krause N, Hayward RD: Prayer beliefs and change in life satisfaction over time. J Relig Health 2013;52:674–694.

41. Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB: Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions. JAMA Intern Med 2015;175:1662–1669.

42. Campbell CL, Williams IC, Orr T: Factors that impact end-of-life decision making in African Americans with advanced cancer. J Hosp Palliat Nurs 2011;41:277–278.

43. Lo B, Ruston D, Kates LW, et al.: Discussing religious and spiritual issues at the end of life: A practical guide for physicians. JAMA 2002;287:749–754.

44. White DB, Engelberg RA, Wenrich MD, et al.: The language of prognostication in intensive care units. Med Decis Making 2010;30:76–83.

45. Salins N, Deodhar J, Muckaden MA: Intensive care unit death and factors influencing family satisfaction of intensive care unit care. Indian J Crit Care Med 2016;20:97–103.

46. Anderson WG, Cimino JW, Ernecoff NC, et al.: A multicenter study of key stakeholders' perspectives on communicating with surrogates about prognosis in intensive care units. Ann Am Thorac Soc 2015;12:142–152.

47. Swinton M, Giacomini M, Toledo F, et al.: Experiences and expressions of spirituality at the end of life in the intensive care unit. Am J Respir Crit Care Med 2017;195:198–204.

48. Steinhauser KE, Voils CI, Clipp EC, et al.: "Are you at peace?": One item to probe spiritual concerns at the end of life. Arch Intern Med 2006;166:101–105.

49. Pargament KI, Koenig HG, Tarakeshwar N, Hahn J: Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. J Health Psychol 2004;9:713–730.

50. Davidson JE, Powers K, Hedayat KM, et al.: Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. Crit Care Med 2007;35:605–622.

51. Boscaglia N, Clarke DM, Jobling TW, Quinn MA: The contribution of spirituality and spiritual coping to anxiety and depression in women with a recent diagnosis of gynecological cancer. Int J Gynecol Cancer 2005;15:755–761.